



SCPOR Saskatchewan Centre for
Patient-Oriented Research



2021-2022

Annual Report to Community

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Mission, Vision, Values

Our Mission

Build capacity and collaborations to conduct responsive, equitable, innovative, patient-oriented research that continuously improves the care and health of Saskatchewan people.

Our Vision

Working together for a healthier Saskatchewan through patient-oriented research.

Our Values

- ▶ Patient-Oriented
- ▶ Capacity-Building
- ▶ Continuous Improvement
- ▶ Equitable
- ▶ Innovative
- ▶ Responsive
- ▶ Collaborative

Funding Partners



Message from the Directors

The 2021-2022 year was one of transition for Saskatchewan Centre for Patient-Oriented Research (SCPOR), both physically (with the Patient Engagement platform and the Indigenous Research Engagement and Expertise (IREE) platform transitioning to new organizations) and in terms of our work, as we prepared for the phase two grant and the new direction it will bring. Much of our operational plan was dedicated to transitioning to a Learning Health System (LHS) approach and developing the systems and infrastructure necessary to carry out our phase two objectives. New governance structures and staffing models were prepared to accommodate the upcoming changes.

Despite limited resources due to COVID-related priorities within our partner organizations, much progress was made with the Health Research Data Platform - Saskatchewan (HRDP-SK), which will be Saskatchewan's first fully integrated and streamlined multi-agency data access platform for health research and analysis. The Master Health Data Sharing Agreement – the first step in realizing a system-wide approach to a common platform for using health system data and analytics to benefit the Saskatchewan health system - was drafted, ensuring general principles, and terms and conditions to contribute and access data in a central repository align with health legislation. Further processes for accessing health data were developed and resources to assist patient-oriented research (POR) teams in accessing and effectively using health data were created.

Patient Partners continued to drive change within SCPOR and in patient-oriented research. Internally, Patient Partners initiated definition changes to better reflect our core values and developed material valueable to new patient-oriented research teams. Their influence in the new Terms of Reference for the Patient Partner Advisory Council (PPAC) will lead to exciting new opportunities for future Patient Partners, including a mentorship program.

In 2022-23, SCPOR will focus on completing remaining work from our phase one grant, including advancing the development of the HRDP-SK and supporting outstanding projects to completion. SCPOR will also begin implementing our phase two grant, with key focuses such as selecting two large Patient-Oriented Research Learning Health System Projects and supporting their implementation. We will also focus on developing and implementing processes to support national patient-oriented research projects, and capacity development will continue with new traineeships.



Jackie Mann,
Executive Director



Malcolm King,
Scientific Director

Oversight

Committee

Clifford Ballantyne
Patient Partner

Jenny Basran
Saskatchewan Health Authority

David Boehm
Ministry of Health,
Government of Saskatchewan

Mark Borgares
eHealth Saskatchewan

Heather Dyck
Patient Partner

Sally Gray
University of Regina

Marg Friesen
Métis Nation Saskatchewan

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Foundation

Delores Pahtayken
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Madeline Press
Saskatchewan Polytechnic

Marek Radomski
University of Saskatchewan

Tracey Sherin
Saskatchewan Health
Quality Council

Candace Skrapek
Patient Partner

Preston Smith
University of Saskatchewan

Tanya Verrall
Saskatchewan Health
Quality Council

Brandy Winquist
Saskatchewan Health
Authority



Patient Partner Advisory Council

Patient Partners:

Cliff Ballantyne

Janet Barnes

Heather Dyck

Diana Ermel

Kathy Evans

Janet Gunderson

Dale Hall

Colleen Hamilton

Maggie King

Candace Skrapek



Indigenous Health Advisory Council

Nicole Akan
File Hills Qu'Appelle Tribal Council

Louise Bird
Patient Partner

Tegan Brock
Metis Nation-Saskatchewan

Tara Campbell
Northern Inter-Tribal Health Authority

Jessica Dieter
Patient Partner

Terri Hansen-Gardner
Patient Partner

Patricia Ironstand
Battle River Treaty 6 Health Centre

Gilbert Kewistep
Knowledge Keeper

Maggie King
Patient Partner

Raymond Laliberte
Metis Addictions Council of Saskatchewan Inc.

Delores Pahtayken
Patient Partner

Adel Panahi
Metis Nation-Saskatchewan

Judy Pelly
Knowledge Keeper

Ian Thomas
Saskatchewan Health Authority



Patient Engagement



Onboarding Guides for Patient-Oriented Research Teams

These useful tools were co-developed with Patient Partners. The working group, comprised of individuals new to POR, developed infographics to support both researchers and Patient Partners to help position new patient-oriented research teams for success. These guides have been shared widely throughout national patient-oriented research circles!

The **Patient & Researcher Connection Site** matches patient-oriented research projects with Patient Partners and shares opportunities for patients to take part in the research in a variety of ways, from participating in surveys to being equal members of the research team. Since its inception, the Patient & Researcher Connection Site has seen...



PATIENT & RESEARCHER
CONNECTION SITE

70

Opportunities
posted

5768

Home page visits

many

Successful
connections made

New definitions to better reflect SCPOR's Values

In early 2022, SCPOR's Patient Partner Advisory Council recommended updating SCPOR's value definitions. Together with SCPOR staff, Patient Partners formed a working group to review and revamp the definitions to ensure they accurately reflected SCPOR's understanding of patient-oriented research and were inclusive of elements required to support the development of a Learning Health System.

Engagement: at the core of everything we do.

Achievements in Patient Engagement over the past year:

- Patient engagement funding and coaching opportunities were identified and began to be developed for the Learning Health System (LHS) program. They included the Stakeholder & Patient Engagement Application Development Award (SPEADA) and the Building Exceptional Teams (BET) Workshop.
- Patient engagement awards for trainees and patient-oriented researchers (SCPOR Trainee Engagement with Patients (STEP) Awards and Patient Engagement Application Development Award (PEADA)) were updated based on feedback from past recipients.
- SCPOR's Patient Engagement platform, including staff and Patient Partners, successfully transitioned from the Saskatchewan Health Quality Council (HQC) to the Saskatchewan Health Authority (SHA). The transition included networking with new SHA colleagues, connecting with SHA Patient Family Leadership Council members and reviewing existing SHA processes based on SCPOR best practices. This transition is part of the long-term sustainability plan for POR in Saskatchewan.
- SCPOR's Patient Partners played a significant role in drafting the Terms of Reference for the phase two grant's Patient Partner Advisory Council (PPAC). One of the highlights was the inclusion of a patient mentorship program.

Level of satisfaction with SCPOR:



Researchers

Trainees

Patient Partners

In 2021-22, Prairie Research Associates (PRA) conducted a program of evaluation of SCPOR's phase I activities and accomplishments. Among the findings were high levels of satisfaction with SCPOR! Learn more about the evaluation at scpor.ca/scpor1evaluation.

Methods

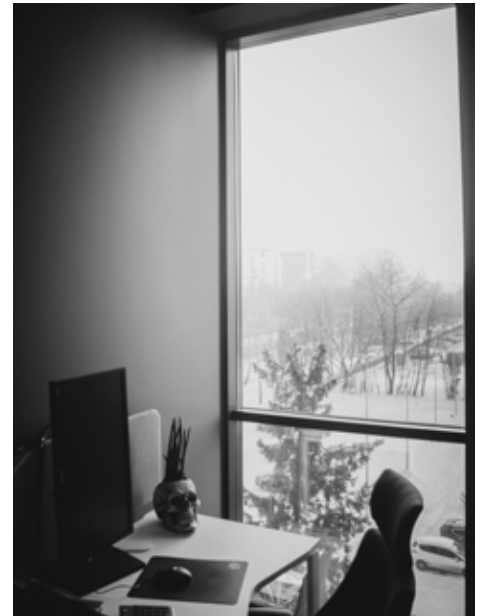
The Methods platform focused on the transition to a Learning Health System (LHS) during the reporting period and offered a three-part series of LHS Workshops:

► **Understanding Learning Health Systems: Informing Saskatchewan COVID-19 Policy** created an understanding of LHS, how they can be applied to the Saskatchewan context and why patient engagement is a crucial aspect to their success. Clinician researchers Dr. Gary Groot and Dr. Jenny Basran discussed key characteristics of an LHS, examples of LHS being utilized to inform policy during the COVID-19 pandemic and their importance continuing into the future.

► **PROMs, PREMs and Patient-Centred Care** focused on how Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) can contribute to patient centred care in an LHS. These sessions created an understanding of LHS, how they can be applied to the Saskatchewan context and why patient engagement is a crucial aspect of their success.

► SCPOR partnered with the BC SUPPORT Unit and invited Danielle Lavallee, Lena Cuthbertson and Rick Sawatsky to present **Reflections from British Columbia: What our patients and stakeholders are telling us about the priorities for patient-centred measurement.** The session focused on the meaning of patient-centred measurement (PCM), including PROMs and PREMs, patient and stakeholder priorities for collecting and analyzing PCM data and reporting and using PCM results.

After attending the three-part LHS series, participants had an increased understanding of PROMs, PREMs, key characteristics of an LHS and the importance of progressing towards Learning Health Systems in the future. Respondents reported sessions were informative with engaging guest speakers.



PORLET Validity Testing

In 2021, the Patient-Oriented Research Level of Engagement Tool (PORLET) underwent validity assessment. A team of staff and Patient Partners incorporated changes based on the feedback, including adding a companion guide, updating the language to make it less confusing and reorganizing the criteria cues. PORLET 2.0 was launched as an updated version of the original product. It provides a simple way to consistently and fairly measure patient engagement when reviewing or writing grants or abstracts or training those new to POR.

	1	2	3	4	5	Notes
Engagement	Engagement is not mentioned in the document.	Engagement is mentioned in the document.	Engagement is mentioned in the document.	Engagement is mentioned in the document.	Engagement is mentioned in the document.	
Patient-Reported Outcome Measures (PROMs)	There is no mention of PROMs in the document.	There is a mention of PROMs in the document.	There is a mention of PROMs in the document.	There is a mention of PROMs in the document.	There is a mention of PROMs in the document.	
Engagement Methods	There is no mention of engagement methods in the document.	There is a mention of engagement methods in the document.	There is a mention of engagement methods in the document.	There is a mention of engagement methods in the document.	There is a mention of engagement methods in the document.	
Other Engagement Tools	There is no mention of other engagement tools in the document.	There is a mention of other engagement tools in the document.	There is a mention of other engagement tools in the document.	There is a mention of other engagement tools in the document.	There is a mention of other engagement tools in the document.	
Other	There is no mention of other criteria in the document.	There is a mention of other criteria in the document.	There is a mention of other criteria in the document.	There is a mention of other criteria in the document.	There is a mention of other criteria in the document.	

Creating Cycles of Improvement

The Methods platform continued to focus on building the infrastructure needed to support SCPOR's Learning Health System and offered a session titled ***Introduction to SCPOR's Patient-Oriented Research Learning Health System Projects.***

The session provided an introduction to SCPOR's Patient-Oriented Research Learning Health System Projects as well as information about how to complete an LHS Expression of Interest and Stakeholder and Patient Engagement Application Development Award (SPEADA) submission. The first LHS Projects SCPOR will support will be selected in year one of SCPOR's phase two grant.



Data Services



Since May of 2021, sponsors and staff from the Ministry of Health (MOH), Saskatchewan Health Authority (SHA), eHealth Saskatchewan (eHealth), Saskatchewan Health Quality Council (HQC), Saskatchewan Cancer Agency (SCA) and SCPOR have been working to create Saskatchewan's first fully integrated and streamlined multi-agency data access platform for health research and analysis. This new platform is called Health Research Data Platform - Saskatchewan (HRDP-SK).

The HRDP-SK is a platform that streamlines the process for researchers to access health data. The data will be housed in a central repository and governed by a Master Health Data Sharing Agreement (MHDSA). HRDP-SK users are supported with consultations and training. They will be provided access to extensive resources including a data dictionary and database overviews that will support increased data literacy and effective use of data.

The HRDP-SK will build significant research capacity and may be leveraged in the future to build capacity for all secondary data access. The platform will be beneficial to both researchers and data trustees. Researchers will have timely, appropriate, reliable, and predictable access to health system data in a remote access environment. The HRDP-SK staff and data trustees will work collaboratively to implement standardized and efficient processes for managing data access requests and data sharing, thus minimizing variation, redundancies and inefficiencies.

The processes developed to support data access requests are aligned with the national standards produced by the Health Data Research Network (HDRN) to guide the implementation of data access for research throughout the country.



Data services was able to provide a notable data linkage in the SHRF/SCPOR supported *Care pathways analytics: Integrating patient-centered outcomes in economic evaluations of care pathways in Saskatchewan*. The overall goal of the research project was to evaluate the clinical and economic impacts of the Chronic Obstructive Pulmonary Disease Care Pathway Program (COPD-CPP). The COPD-CPP was implemented in the Regina area of the Saskatchewan Health Authority in September 2017. Researchers aimed to analyze the impact of COPD-CPP on healthcare utilization and healthcare costs by comparing intervention and control groups using state sequence analysis and sequence cluster analysis

In establishing the intervention group, it was determined that it would not be possible to identify with a high degree of certainty which individuals were enrolled in the pathway by using admin-data only, therefore a data sharing agreement to access the master list of participants was put in place. The list of participants of the COPD-CPP was deidentified to ensure privacy and consistency using the same algorithm that would allow for linkages with the administrative health databases.

2021-22 Data Milestone Achievements

created
MHDSA

to eliminate
project specific
data sharing
agreements

developed
**Streamlined
Data Processes for:**

- Data Access Request for Researchers
- Data Integration to standardize how datasets are added to the HRDP-SK Central Repository
- Coordinated process for data trustees to assess data access requests for research

developed
**Data
Literacy
Materials**

to support
research teams

5 data
bases to
be
included

initiated
**Processes
to Secure:**

- cloud-based storage and a secure research environment for the HRDP-SK to support data access requests
- a request management system to automate the Data Access Request Process for researchers

developing
**Central
Repository**

where data will
be housed at
eHealth



Research

to Action



In order for physicians providing developmental or psychiatric pediatric care to be truly client-centred, the Saskatchewan Health Authority supported project ***Preference of developmental behavioural pediatrics patients in accessing services during and post pandemic*** found that most parents preferred a hybrid of access to both in-clinic and virtual care that should compel availability of both options to patients. Next steps might include repeating the initial survey in other areas of medicine and developing best practice clinical guidelines for a hybrid model of in-person and virtual care.

As part of the **COVID-19 Evidence Support Team**, literature was reviewed and synthesized to provide individuals leading the vaccine delivery with evidence based recommendations for its roll out. As the vaccine roll out was implemented across the province, two types of comprehensive evaluations of the process (realist and developmental) were conducted.

A **framework for the standardized development, evaluation and maintenance of clinical pathways in Saskatchewan** is in development. The components of this framework include formal approval process, proposed SHA reporting structures, team roles and responsibilities, work plan checklist, pathway prototype checklist, Patient Family Partner orientation package, shared decision-making framework, maturity matrix evaluation tool, replication checklist and project documentation tools and templates.

A **framework for the implementation of an LHS within SHA**, including an LHS glossary (to ensure cross-disciplinary operational term definitions) is in development. To ensure applicability across disciplines and departments within the organizations, an SHA LHS Community of Practice has been established.

Knowledge

Translation



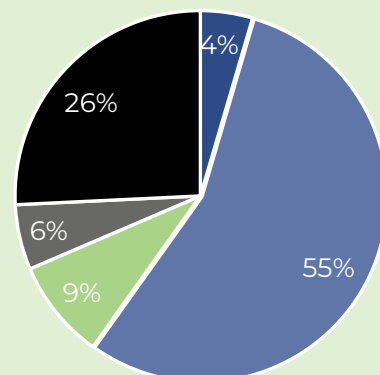
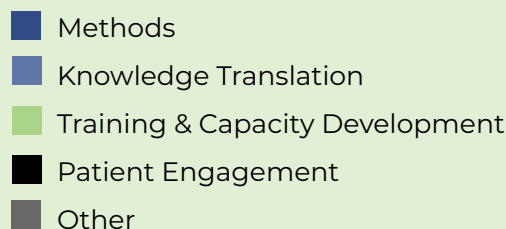
James Lind Alliance (JLA) - Priority Setting Partnership: As a result of work conducted from 2019- 2021, a top 10 list of research priorities for Obstructive Sleep Apnea (OSA) in Saskatchewan was published. After learning there were many questions from the public that were already answered but were not easily accessible to OSA patients and families, the Respiratory Research Centre (RRC) developed three animated short videos in an attempt to close the knowledge gap. Patients and families of OSA patients from the JLA final workshop as well as RRC patient advisors were invited to participate in the production of the videos.

Saskatchewan Polytechnic's **#WeHearYou** advocated for healthcare workers dealing with the pandemic. The team disseminated KT to support health care workers, and provided resources for leadership and management for combating burnout during the pandemic.

Trans Health Navigator Project, a Saskatchewan Health Research Foundation/SCPOR Sprout grant recipient out of SHA, supports trans and gender diverse (TGD) individuals in consulting with a peer navigator to provide information and connect clients with healthcare resources in the province and assist in identifying and connecting clients with physicians and other healthcare providers who have a reputation for providing safe, high-quality care for TGD individuals. Navigators were available to provide 70 healthcare providers education and other services about trans and gender diverse people. Learn more about this project in impact stories!

Saskatchewan Polytechnic's **Farmers and Ranchers Mental Health (FARMH) Initiative** team offered mental wellness sessions to youth in schools and free phone sessions about farmer/ rancher mental health to producers. The work has started the conversation and opened peoples' eyes to the potential of virtual care via virtual reality rather than solely telehealth.

Of the 264 service requests directed to specific SCPOR platforms, over half were related to Knowledge Translation:

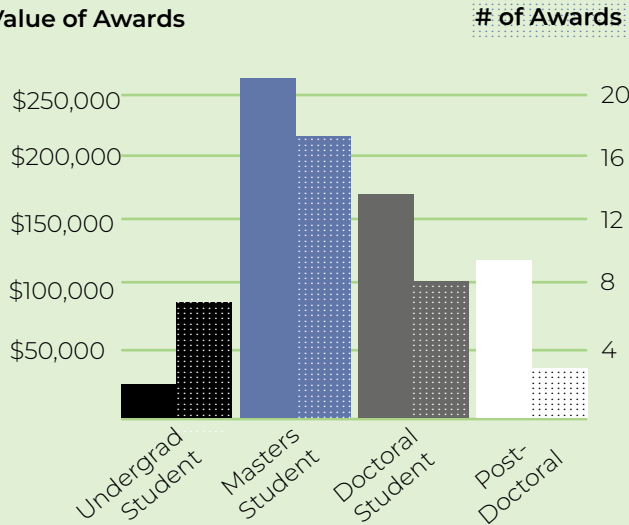


Training and Capacity

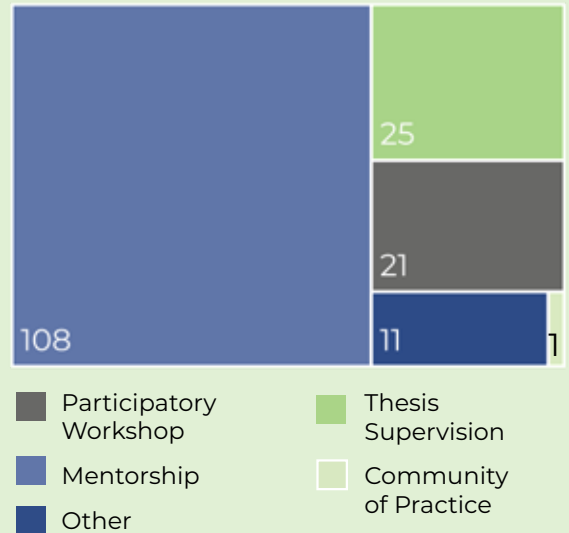
Development

In 2021-22, SCPOR, in partnership with University of Saskatchewan, University of Regina and Saskatchewan Polytechnic, supported several traineeships and patient-oriented research grants. Traineeships were awarded to 35 students, valued at \$584,085. Additionally, SCPOR conducted several TCD building activities.

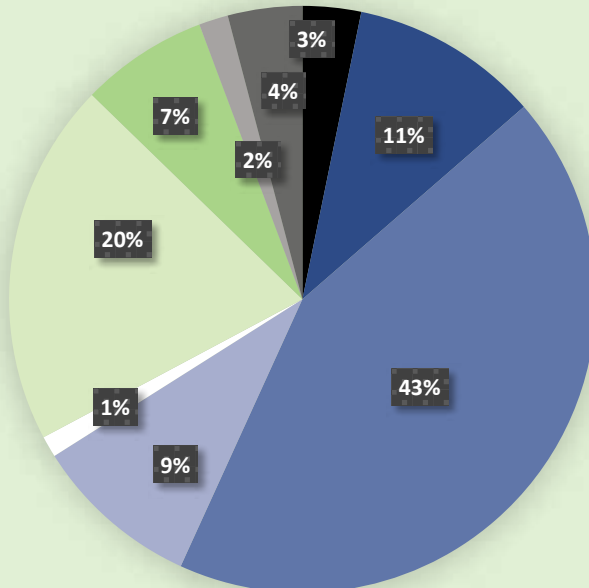
Value of Awards



Training & Capacity Building Activities



Participants in Training & Capacity Building Activities



- SUPPORT Unit Staff (22)
- Patients (71)
- Researchers/ Academics (295)
- Trainees (63)
- Clinical Scientists (8)
- Health System Practitioners (137)
- Health System Managers (48)
- Federal / Provincial Reps (11)
- Other (28)

Past trainees were surveyed with the following results:

How has your POR experience impacted your research approach, clinical practice or your daily work?

- Strengthened capacity to engage patients in research/work (21)
- Prudence in research (11)
- Recognize the value of lived experience in research/work (10)
- Importance of building relationships in research (7)
- Serving as a Patient Partner (1)
- Learned about qualitative research (1)

Has your experience as a SCPOR trainee impacted your career professional trajectory?



Do you still practice patient-oriented research?

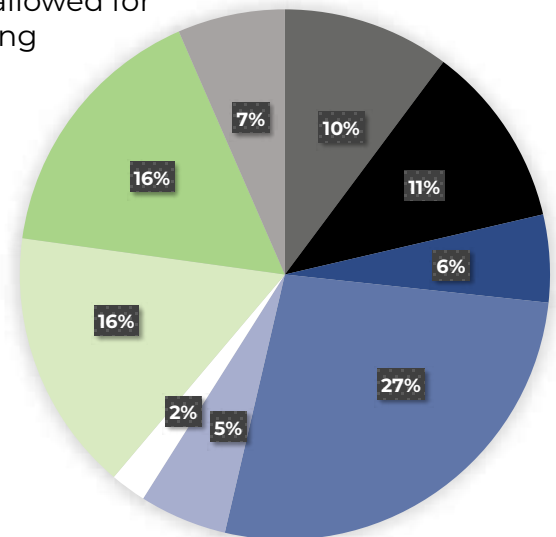


Saskatchewan Health Research Showcase

The Saskatchewan Health Research Showcase held in Fall 2021, a collaboration between SCPOR and the Saskatchewan Health Authority (SHA), took place virtually over two half days and featured two keynote addresses, 19 presentations and 115 e-posters. The event attracted 415 registrants from throughout the province and engaged Patient Partners, health system professionals, researchers, students and more. Using a virtual platform allowed for increased rural participation, with 20% of attendees residing outside the two major centres in Saskatchewan.

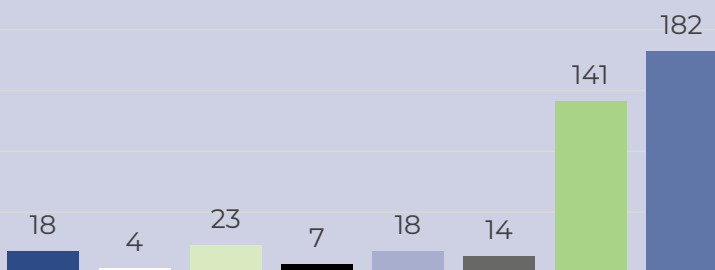
Showcase Attendance by Role

- Health System Practitioners (46)
- SHA Staff (66)
- Student Partners (22)
- Students (67)
- Researchers / Academics (111)
- Other (27)
- SCPOR Staff (22)
- Health System Managers/Leaders (42)
- SCPOR Trainees (9)



Showcase Attendance by Location

- Canada - outside SK
- SK North East
- SK South East
- Regina Area
- International
- SK North West
- SK South West
- Saskatoon Area



Indigenous Research

Engagement & Expertise

Engaging Indigenous Voices

A diverse range of Indigenous voices and perspectives have engaged and shaped SCPOR activities this fiscal year:

- ▶ The direct involvement of Indigenous Knowledge Keepers, community members and Patient Partners in the design of two new training modules to be offered by SCPOR: Indigenous Data Sovereignty and Indigenous Research Methodologies.
- ▶ Nine Indigenous trainees with continued funding until mid-2021 under the SCPOR/Indigenous Peoples' Health Research Centre (IPHRC) Trainee Awards.
- ▶ Regular ongoing engagement with two guiding Knowledge Keepers who serve as a resource for SCPOR researchers and staff members seeking information and advice related to respectful Indigenous engagement at patient, community and organizational levels.

As Canada's first SPOR SUPPORT Unit with a dedicated Indigenous Research and Engagement Expertise (IREE) platform, SCPOR ensures Indigenous voices, knowledges, values and rights as they relate to health research are respected, represented and inherent in all SCPOR activities, particularly in the areas of community and patient engagement.

Indigenous Methods & Methodologies

SCPOR is fortunate to have had the opportunity to work with Knowledge Keepers, who are present to provide blessings, prayer and opening remarks at the beginning of major events, orientations, training sessions and workshops to ensure the gathering is conducted in a good way. Elder Gilbert Kewistep began the new year with a pipe ceremony to bring in blessings and prayer for a healthy, productive year for all SCPOR staff members. Knowledge Keepers also contribute life stories and experiences during BRRIC training to inform attendees about the effects of trauma resulting from policies and the lack of resources for Indigenous peoples in their communities.

Researchers are encouraged to build relationships with Indigenous communities and follow cultural protocols such as providing cloth and tobacco in exchange for knowledge and participation in research projects. They have been invited to present on their research projects at Indigenous Health Advisory Council (IHAC) meetings to gain feedback from IHAC members about culturally appropriate research methods, knowledge translation activities and research design, among other things.

IREE staff provide a culturally safe environment when presenting workshops to Indigenous communities and organizations, allowing participants to ask questions and share stories in a safe space without fear of retribution or judgement.

Saskatchewan Polytechnic has worked closely with Elders throughout one La Loche- based project. Virtual reality segments being filmed will include traditional teachings and storytelling and Elders speaking to one's worth and connection to culture. Elders also enabled the team to incorporate Indigenous language within the recordings.

Knowledge Keepers

14 IHAC members

Cultural Protocol

PPAC reps

Gift of Tobacco

Elders & Staff Management

Representation on Oversight Committee



Impact

TRANS Health

Little research data exists about trans people in Saskatchewan. Principal Investigator Dr. Stephanie Madill and Dr. Megan Clark were asked by a community organization supporting people with lived experience to address this issue. They established a multi-disciplinary team of 28-30 members, among them researchers, data analysts, social workers, a physiotherapist and family practitioners, many of whom also have lived experience. People with lived experience identified the priority - wanting better access to safe care from healthcare providers who have interest in and knowledge about trans health issues, and the research objectives - determining health care access for people who are trans and gender diverse in Saskatchewan and determining the impact of health navigators through a one-year pilot. People with lived experience have been meaningfully included in every stage of the project and have been equal decision makers throughout. They determined a need for immediate action rather than future results, leading to the implementation of navigators, one in Regina and one in Saskatoon, both of whom bring lived and professional healthcare experience to their roles. The project is funded by the Saskatchewan Health Research Foundation and SCPOR and collaborations exist with the community, clinicians, academics and policy makers.

Among the project highlights, after learning that changing legal names and gender markers was a major barrier to care, the navigators became notaries public and held several clinics to assist clients thereby improving their ability to access healthcare, seek employment, attend school and participate socially. The most notable outcome from the project is understanding the importance and need for navigators. SCPOR is proud of the immediate impact the navigators have had connecting 259 clients – including 248 repeat users - with safe and appropriate health care and providing education and other services to 70 healthcare providers, 36 of whom contacted the navigators more than once. These relationships will help incorporate new knowledge into the health system, improving accessibility, and address some of the challenges faced by the navigators, including the lack of physicians with the interest or knowledge needed to provide primary healthcare for people who are trans and gender diverse and the long wait times to see these physicians. SCPOR is excited about the potential for sustainability; due to its success (93% of survey respondents were satisfied or very satisfied with the navigator services provided), at the pilot's end, a community organization sought bridge funding to extend the navigator role beyond the project.

Preliminary meetings with the Ministry of Health to seek long-term funding for navigators situated within the healthcare system have occurred. While the full impact is still under analysis, the team hypothesizes that emergency and urgent care visits will decline once patients have access to trans-friendly primary care providers. Impacts will be further assessed through the narrative analysis of the navigators' journals, including deidentified client stories and post-service interviews with clients and support people.

BC BRRIC Training

As a result of the COVID-19 pandemic, Building Research Relationships with Indigenous Communities (BRRIC) training sessions pivoted to online delivery in 2020, leading to an increased interest from participants outside of Saskatchewan. In May 2021, the First Nations Health Authority (FNHA) in British Columbia (BC) reached out to SCPOR to discuss the possibility of BRRIC delivery to the organization. Because BRRIC is primarily aimed at audiences based in Saskatchewan in that it focuses on Saskatchewan-specific statistics and histories, it was decided that an adaptation to suit a BC audience was necessary.

Subsequently, SCPOR's Indigenous Research Engagement and Expertise (IREE) platform reached out to the BC SUPPORT Unit for advice and a request for collaboration to adapt BRRIC content. A meeting was held between SCPOR, BC SUPPORT Unit and BC Network Environment for Indigenous Health Research (BC NEIHR) to discuss moving forward. It was decided that BC NEIHR would conduct a search for two indigenous PhD students to complete the adaptation of content to a BC context, which would be funded by the BC SUPPORT Unit.

In October 2021, the adaptation was completed. The IREE platform, along with staff and Knowledge Keepers from FNHA, reviewed the content to ensure it was culturally accurate and appropriate for a BC audience. In December 2021, BC BRRIC training was delivered in a half-day session. Attendees represented several organizations, with staff from BC SUPPORT Unit, BC NEIHR, FNHA and Research Ethics BC and representatives from Simon Fraser University, University of British Columbia, Vancouver Island University and the University of Northern BC. Feedback from the delivery was positive, with the majority of respondents reporting a great level of understanding of the content during evaluations, such as the impact of colonialism and residential schools on Indigenous peoples in Canada and health issues that affect Indigenous peoples and communities. Suggestions for future delivery included partnerships with BC SUPPORT Unit to ensure the workshops stays in active rotation for British Columbia and/or the creation of a memorandum of understanding between the partner organizations for the use of course material and content.

Collaboration





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